

AGENDA

Monday, December 6, 2004

- 8:30 a.m. Opening Remarks
Patricia A. Grady, Ph.D., R.N.
Director
National Institute of Nursing Research
National Institutes of Health
- 8:40 a.m. Charge to the Panel and Participants
Susan Rossi, Ph.D., M.P.H.
Deputy Director
Office of Medical Applications of Research
Office of the Director
National Institutes of Health
- 8:50 a.m. Conference Overview and Panel Activities
Margaret M. Heitkemper, Ph.D., R.N., F.A.A.N.
Conference and Panel Chairperson
Professor and Chair
Department of Biobehavioral Nursing and Health Systems
University of Washington School of Nursing

I. What Defines the Transition to the End of Life?

- 9:00 a.m. A Demographic and Prognostic Approach To Defining the End of Life
Elizabeth Lamont, M.D., M.S.
Assistant Professor of Medicine
Massachusetts General Hospital Cancer Center
Harvard Medical School
- 9:20 a.m. Preferences and Changes in the Goals of Care
Thomas Finucane, M.D.
Professor of Medicine
The Johns Hopkins University School of Medicine
- 9:40 a.m. Discussion
Participants with questions or comments for the speakers should proceed to the microphones and wait to be recognized by the panel chair. Please state your name and affiliation. Questions and comments not heard before the close of the discussion period may be submitted at the registration desk. Please be aware that all statements made at the microphone or submitted later are in the public domain.

Monday, December 6, 2004 (continued)

II. What Outcome Variables Are Important Indicators of the Quality of the End-of-Life Experience for the Dying Person and for the Surviving Loved Ones?

10:10 a.m. Overview of the Domains of Variables Relevant to End-of-Life Care

Betty R. Ferrell, Ph.D., R.N., F.A.A.N.

Research Scientist and Professor

Department of Nursing Research and Education

City of Hope National Medical Center

10:30 a.m. Measuring Outcomes Prospectively

Karen E. Steinhauser, Ph.D.

Associate Faculty Scholar

Veterans Affairs and Duke Medical Centers

Duke University Institute on Care at the End of Life

10:50 a.m. Measuring Outcomes Retrospectively

Joan Teno, M.D., M.S.

Professor of Community Health and Medicine

Center for Gerontology and Health Care Research

Brown University

11:10 a.m. Handling Missing Data

Paula Diehr, Ph.D.

Professor

Biostatistics and Health Services

Department of Biostatistics

University of Washington

11:30 a.m. EPC Presentation: Summary of the Evidence

EPC Speaker TBA

RAND

11:50 a.m. Discussion

12:30 p.m. Lunch

III. What Patient, Family, and Health Care System Factors Are Associated With Improved or Worsened Outcomes?

1:30 p.m. Racial, Cultural, and Ethnic Factors

LaVera M. Crawley, M.D., M.P.H.

Center for Biomedical Ethics

Stanford University

Monday, December 6, 2004 (continued)

III. What Patient, Family, and Health Care System Factors Are Associated With Improved or Worsened Outcomes? (continued)

- 1:50 p.m. Key Factors Affecting Dying Children and Their Families
Pamela S. Hinds, Ph.D., R.N.
Director
Nursing Research
St. Jude Children's Research Hospital
- 2:10 p.m. Key Factors Affecting Those Dying With Dementia
Greg A. Sachs, M.D.
Chief
Section of Geriatrics
Professor of Medicine
Department of Medicine
University of Chicago
- 2:30 p.m. Health Care System Factors
R. Sean Morrison, M.D.
Hermann Merkin Professor of Palliative Care
Hertzberg Palliative Care Institute
Mount Sinai School of Medicine
- 2:50 p.m. EPC Presentation: Summary of the Evidence
EPC Speaker TBA
RAND
- 3:10 p.m. Discussion

IV. What Processes or Interventions Are Associated With Improved or Worsened Outcomes?

- 4:00 p.m. Interventions To Manage Symptoms at the End of Life
Charles F. von Gunten, M.D., Ph.D.
Medical Director
Center for Palliative Studies
San Diego Hospice & Palliative Care
San Diego School of Medicine
University of California

Monday, December 6, 2004 (continued)

IV. What Processes or Interventions Are Associated With Improved or Worsened Outcomes? (continued)

- 4:20 p.m. Interventions To Enhance Communication Among Patients, Providers,
and Families
James A. Tulsky, M.D.
Director
Center for Palliative Care
Duke University Medical Center
- 4:40 p.m. Interventions To Enhance the Spiritual Aspects of Dying
Harvey M. Chochinov, M.D., Ph.D., FRCPC
Canada Research Chair in Palliative Care
Director
Manitoba Palliative Care Research Unit
Professor of Psychiatry
University of Manitoba
Canada
- 5:00 p.m. Adjournment

Tuesday, December 7, 2004

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| 8:30 a.m. | Interventions To Facilitate Withdrawal of Life-Sustaining Treatments
J. Randall Curtis, M.D., M.P.H.
Associate Professor of Medicine
University of Washington |
| 8:50 a.m. | Interventions To Facilitate Family Caregiving
Susan C. McMillan, Ph.D., A.R.N.P., F.A.A.N.
Lyall and Beatrice Thompson Professor of Oncology Quality of Life Nursing
College of Nursing
University of South Florida |
| 9:10 a.m. | Interventions To Enhance Grief Resolution
Margaret Stroebe, Ph.D., h.c.
Associate Professor of Clinical Psychology
Department of Clinical Psychology
Utrecht University
The Netherlands |

Tuesday, December 7, 2004 (continued)

IV. What Processes or Interventions Are Associated With Improved or Worsened Outcomes? (continued)

9:30 a.m. EPC Presentation
 EPC Speaker TBA
 RAND

9:50 a.m. Discussion

V. Cross-Cutting Considerations

10:50 a.m. Ethical Considerations in End-of-Life Care and Research
 David Casarett, M.D., M.A.
 Assistant Professor
 Division of Geriatrics
 Center for Health Equity Research and Promotion at the Philadelphia Veterans
 Affairs Medical Center
 University of Pennsylvania

11:10 a.m. Lessons From Other Nations
 Irene J. Higginson, M.D., Ph.D.
 Professor
 Department of Palliative Care and Policy
 King's College London
 United Kingdom

11:30 a.m. Discussion

12:00 p.m. Adjournment for Panel Deliberations

Wednesday, December 8, 2004

9:00 a.m. Presentation of the State-of-the-Science Statement

9:30 a.m. Public Discussion
 The panel chair will call for questions and comments from the audience on the draft consensus statement, beginning with the introduction and continuing through each subsequent section in turn. Please confine your comments to the section under discussion. The chair will use discretion in proceeding to subsequent sessions so that comments on the entire statement may be heard during the time allotted. Comments cannot be accepted after 11:30 a.m.

Wednesday, December 8, 2004 (continued)

11:00 a.m. Panel Meets in Executive Session

Panel meets in executive session to review public comment. Conference participants are welcome to return to the main auditorium to attend the press conference at 2:00 p.m.; however, only members of the media are permitted to ask questions during the press conference.

2:00 p.m. Press Conference

3:00 p.m. Adjournment